“Self-Advocacy in the Era of Precision Medicine” (Rome Madison) [#133]

Brad Power
February 26, 2025

“Our goal is to inform and empower patients in ways to advocate for a precision medicine approach to their care, and empower and prepare those patients and their family members to be more effective partners in their care.” – Rome Madison

“We want as many patients as possible to have access to these innovative therapies and this genetic information. We also want to ensure that patients and their loved ones are working with healthcare providers that have their best interests at heart and who are willing to partner with patients to make shared decisions for their care.” – Rome Madison

“How much impact can you make? Not just on your family and the people around you. But your faith, your fighting, and your advocacy can make a larger impact on the world around you.” – Rome Madison

Meeting Summary

Cancer patients and their loved ones face a lack of access to clinicians and institutions who routinely incorporate genetic insights into total patient care. Many people are not aware of precision medicine and don't feel knowledgeable enough or empowered to advocate for this approach to their care.

Rome Madison, President, Genomic Selling Solutions, is uniquely qualified to lead a discussion on how you can build your knowledge about precision medicine and advocate for your care. He has led sales, product development, and product strategy in the cancer diagnostics industry for more than 20 years, including the very first molecular assay to help oncologists personalize adjuvant therapy. His father is a colon cancer survivor, for whom he was able to be in his surgical resection and follow his tumor tissue through the diagnostic pathways to ensure he had access to precision medicine.

Why do you need to know about precision medicine to advocate for your care?

- **Get better outcomes**: The more you understand about precision medicine (treatments that are selected because of your unique cancer profile), the better you can partner with your healthcare team to ensure you receive the most personalized and comprehensive care possible. Numerous published studies across cancer types have demonstrated that a patient with a genetic mutation, treated with a drug that selectively targets that mutation can result in better response and improved survival compared to standard chemo when given at the right time. Precision medicine uses genetic and molecular test results about your cancer to guide your treatment decisions toward targeted therapies or clinical trials that may be more effective.
- **Avoid missing opportunities**: Without this knowledge, you may not realize there are additional testing or treatment options beyond the standard of care that your doctor

initially recommends. Advocating for comprehensive genomic profiling of your cancer can uncover actionable mutations that could personalize your treatment.
- **Have agency**: Staying informed about the latest advances in tests and treatments empowers you to have more informed discussions with your doctors about the best care plan for your unique cancer and occasionally tip the balance to favor your preferences.

How can you build your confidence to engage in your cancer care decisions?

- **Educate yourself**: Educate yourself about your disease and testing and treatment options, and bring your questions and ideas to your doctors. Feel empowered to ask questions and express your needs.
- **Ask questions**: Don’t be afraid to make sure you understand as much as you can about the testing and treatment decisions that are being made. Also ask your doctors for educational resources they may have of genetic and genomic tests that may be useful for you.
- **Advocate for tests**: Get frequent testing. Research whether novel tests, like liquid biopsies, transcriptomics, or proteomics, might be useful for you. Persistently request relevant testing. Even if your doctor is unfamiliar with the test, you should continue to advocate for tests that could inform your care, like comprehensive genomic profiling or liquid biopsies.
- **Find a consultative doctor**: Find an expert in your specific disease, preferably at a cancer research center, who is willing to partner with you. Some community hospitals have a relationship with cancer research centers and can either refer you to a specialist, or consult with them virtually on your care.
- **Connect**: Connect with other patients through patient communities.

What questions should you ask your doctor?

General

- “Could you please explain those complex terms in simpler language?”
- “My understanding is [X], is that correct?”
- “What are the consequences of my diagnosis for my family members?”
- “What is driving my tumor growth?”

Testing

- “What additional tests should I get to possibly identify new treatment options, personalize my care, and help guide my treatment?”
- “Can I get a comprehensive genomic profile?”
- “Is a liquid biopsy an option for me?”
- “Why is biomarker testing needed?”
- “How will the test be done?”
- “What is the cost of the test?” “Is the test covered by insurance?”
- “Can I get a copy of my test report?”
- “How frequently should I get tests?”

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Treatment

- “Are there alternative treatment options (besides the standard treatment)?”
- “Can I get a second opinion on my diagnosis and treatment plan?”
- “Under what circumstances will you change treatment if current options are not effective?”
- “Should I consider clinical trials?”
- “How can I find clinical trials that would be relevant to me?”
- “Will the treatment you are proposing hurt my chances of responding to future treatments or preclude me from accessing future treatments?”

How can you learn more about advocating for yourself?

- Follow up with Rome Madison to learn more about his podcast "Genetics for Healthcare" and the resources he provides for patients.
- Contribute to a directory of recommended doctors and specialists that cancer patients can reference.
- See our many discussions with “citizen scientists” who have educated themselves about their testing and treatment options and advocated for their best treatments, such as:
    - “A Guy with Two Cancers Explores Treatments and Life” (Burt Rosen) [#112]
    - “A Rogue Cancer Patient Gets Better Outcomes” (Ari Akerstein) [#109]
    - “An Engaged Caregiver” (Rochelle Prosser, RN, CLNC) [#101]

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Meeting Notes

KEYWORDS

Precision medicine, self-advocacy, genetic testing, cancer care, molecular assay, patient empowerment, liquid biopsy, clinical trials, germline genetic testing, diagnostic pathways, oncology, healthcare providers, patient advocacy, innovative therapies, genetic insights.

SPEAKERS

Rome Madison (64%), Roger Royse (13%), Cindy Ness (7%), Rick Davis (6%), Chris Apfel (6%), Robb Owen (2%)

CHAT CONTRIBUTORS

David Plunkett, Chris Apfel, Ari Akerstein, Brian Kane, Rick Davis, Hazel, Ryan Ramanujam, Roger Royse

SUMMARY

Rome Madison, President of Genomic Selling Solutions, discussed the importance of self-advocacy in precision medicine. He emphasized the need for patients to ask detailed questions to their doctors, such as understanding complex terminology and requesting comprehensive genomic profiles. He shared his personal experiences, including his mother's struggle with mental health and his father's colorectal cancer survival. He highlighted the role of liquid biopsies and minimum residual disease (MRD) testing in cancer care. The discussion also touched on the challenges of accessing innovative therapies and the importance of patient advocacy in driving better healthcare outcomes.

OUTLINE

Rome Madison's Background

- Rome Madison, the president of Genomic Selling Solutions, led a discussion on building knowledge around precision medicine and self-advocacy.
- He has many years of experience in the diagnostics industry.
- His current podcast: “Genetics for Healthcare: A Podcast for Patients, targets people who are battling genetic diseases like cancer, cardiovascular disease, sickle cell, and other rare conditions
- During a period of unemployment, his mother struggled with mental health and homelessness which led him to a season of self-discovery and fortuitous events that led to his career in precision medicine.
- During the year he was unemployed, he got an opportunity to interview for a job with the first molecular oncology company offering tumor testing. For three months he taught himself by studying in bookstores and medical libraries before he secured one of ten sales regions at Oncotech, the 1st of its kind precision medicine test.
- His father was diagnosed with colorectal cancer, which further motivated him in his career.

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Rome's Experience with Precision Medicine

- Rome gathered extensive experience in the operating room, watching tumor resections and working with oncologists, pathologist, radiologist and surgeons to apply genetic insights to cancer care.
- His own father was diagnosed with colon cancer, and because he already worked with the surgeon and hospital system, he was able to be in the surgery and follow the tumor tissue as it exchanged hands through surgery and hospital pathology where the diagnosis was made and biomarker and genomic tests were ordered. His father was successfully treated and is a 20 year colon cancer survivor, which has solidified his belief in the potential of precision medicine to cure or manage cancer.
- Healthcare providers need to go the extra mile to ensure patients understand their care and the role of self-advocacy.
- The goal of his podcast is empowering patients and their families to be effective partners in their care.

Questions to Ask Your Doctor

- Rome shared questions from his podcast interviews with patients and experts, aimed at helping patients advocate for themselves:
- “Could you please explain those complex terms in simpler language?”
- “My understanding is [X], is that correct?”
- “What additional data could I get to personalize my care and what additional tests might help guide my treatment?”
- “Are there alternative treatment options?”
- “Under what circumstances will you change treatment if current options are not effective?”
- “Can I get a comprehensive genomic profile?”
- “What are the consequences of my diagnosis for my family members?”
- “Should I consider clinical trials?”
- “How can I find clinical trials that would be relevant to me?”
- “Why is biomarker testing needed?”
- “How will the test be done?”
- “What is the cost of the test?”
- “Is the test covered by insurance?”
- “Can I get a copy of my biomarker test report?”

Challenges and Solutions in Patient Advocacy

- Cindy Ness raised concerns about the current healthcare system's ability to support patient advocacy and the need for better-informed doctors.
- Rome acknowledged the challenges but emphasized the importance of starting a dialog with doctors to ensure they are partners in patient care.
- Roger Royse shared his experience of having to advocate for himself to understand his proteomics report and the importance of persistence.
- Rome and Roger discussed the variability in testing and the need for continuous advocacy to ensure patients receive the best care.

Discussion on Liquid Biopsies and Nutritional Advocacy

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- Rick Davis and Rome discussed the importance of getting to a center of excellence for better treatment and the need for frequent testing in certain diseases.
- Rick emphasized the role of educated patients in getting better treatment and the importance of liquid biopsies in monitoring disease progression.
- Robb Owen asked about the role of nutritional and supplemental approaches in cancer treatment, and Rome shared his wife's perspective on naturopathic care.
- Rome and Chris Apfel discussed the benefits of liquid biopsies and the need for more advocacy to ensure doctors are familiar with and willing to use these tests.

Next Steps

- Cindy Ness suggested creating a repository of doctors who are knowledgeable and supportive of patient advocacy, and Roger acknowledged ongoing efforts to develop such a resource.

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TRANSCRIPT

Roger Royse
This is the Cancer Patient Lab weekly meeting where we have a presentation today on self advocacy.

Before we start, I want to remind everybody that this is just information. It is not medical advice. I'm certainly not a doctor, and you should seek independent medical advice for your particular situation.

The Cancer Patient Lab is a 501(c)(3) nonprofit organization that is supported through contributions and public support. If you like what we're doing, please go to our website to make a donation.

Today's presentation and discussion is going to be led by Rome Madison. He's the president of Genomic Selling Solutions. He's going to lead a discussion on how you can build your knowledge around precision medicine and advocate for your care. He's led sales, product development and strategy in cancer diagnostics for more than 20 years, including the very first molecular assay to help oncologists personalize adjuvant therapy. His father is a cancer survivor. He was able to be in a surgical resection and follow his tumor tissue through the diagnostic pathways to ensure he had precision medicine.

Rome Madison 1:38
Thank you so much. Thank you, Brad, for just your partnership and being a champion for other patients and for innovation in the space.

Sorry to disappoint you, but I'm not a doctor. I'm not a scientist. But I have been in this industry long enough to see its infancy and grow and evolve with it, grow and evolve with the science, and also growing involved with the literature. I've been in leadership, building companies, launching new diagnostic tests that inform cancer care for the greater part of 20 years. Today, I have a podcast called “Genetics for Healthcare”. It's a podcast for patients, and our goal is to inform and empower patients in ways to advocate for themselves and their doctors for a precision medicine approach to their care, and empower and prepare those patients and their family members to be more effective partners in their care.

I met Brad some time ago at the Harvard Medical School, at a think tank, and Brad, at that time, was getting treatment. His hair looked like mine (he was bald), and he made a statement to someone who was a high ranking administrator at a one of the medical schools who was there, I would say, pontificating. I might be a little cynical, but he was talking about the great approach that his institution does, how they sequence everybody, how they consider genetic information. I was struck by Brad's courage when he stood up and said, “I love your institution, and being treated there. I'm sure it's great, but I'm just here to tell you what you're saying is not happening on the front lines.” I just thought it took a lot of courage to do that. I went up to him, and since that time, I interviewed Brad for the Precision Medicine podcast, the first podcast we started,

and the goal of that podcast is to raise the knowledge in the industry, like, “How are we going to make all of this available and affordable for patients?” But it ended up being an industry conversation, and after years of doing that successfully, and it grew, and I think it contributed to the increase in awareness of folks in the industry and the clinical utility and uncovering some of the problems. But the one thing that has been missing since that time, since 2018 when I launched that podcast, is we've had explosive growth. We've had tremendous innovation in the space. But the thing that remains the same is that patients aren't getting access to these innovative therapies. So that's why I do what I do today, and this is what brought me on here to talk to you guys.

I want to give you a little background on why I got here, because I have an unreasonable amount of confidence that we can not only cure cancer, but in some cases, whether it's rare diseases or late stage cancer, we can make this a chronic disease. I have an unreasonable amount of confidence because of the way I got here. This started now, 22 years ago. It has nothing to do with cancer. I’m not necessarily a scientific person by training. There was a year where I was unemployed. I've always been in sales. I've been in healthcare. When I grew up, my mother raised three kids as a single mother. She graduated from college, the University of Texas, with her degree in business, while working full time. That stress on a single woman to take care of family and be the breadwinner – all those things – took a toll on my mother, and she struggled with her mental health for the balance of my life. At this time, when I'm fully grown and my mother's an empty nester, I found out that my mother had really spiraled. Being away, I didn't understand the depth of what was going on. She lost her job. She eventually lost her home. My mother spiraled into a lifestyle of homelessness, and I can't tell you, there's no words to describe that feeling or your view of yourself, and all those things when you go to bed at night and you don't know where your mother is. This is during the time that I was unemployed. My brother, at that time, was going to school at Baylor University. He dropped out of school to try to help my mom, thinking he's trying to help my mom, and he starts selling drugs. Of course, we know how that ends. He gets busted and goes to jail. It was during that time that I got the opportunity to interview and work for the first company that was doing any type of precision medicine. We just called it, “molecular oncology” at the time. But the benefit was, I was unemployed. I had nothing else to do but prepare for these conversations, and so I went to Barnes and Nobles and Borders Books. Remember when we used to go to bookstores to have a cup of coffee? Now we go to coffee stores to read a book. Back then, that was my homework. I was unemployed. I didn't have the money to buy these books, so I would go and study and copy out of the books and put them back on the shelf. The story is that I ended up getting the opportunity. That company was called Oncotech. I'll fast forward the story of my mother and my brother. My mother suffered from homelessness for 11 years, not because she didn't have a place to go to, but that was the state that she was in. What stopped her is she had a massive heart attack. We were able to get her to the hospital, get her care, and she was in an assisted living place for seven years. My mother passed away in 2023 surrounded by family and friends. That story alone is one of the reasons why I have unreasonable confidence in what we can do in this industry. Because after all those years of suffering and having anxiety about what's going on with my mother, I still had faith that someone was looking out for her, and that a better outcome can come from that. And it did. My brother is an electrician today. He turned his life

around. He went back to college. He got his masters. He got his bachelor's degree. He's doing well.

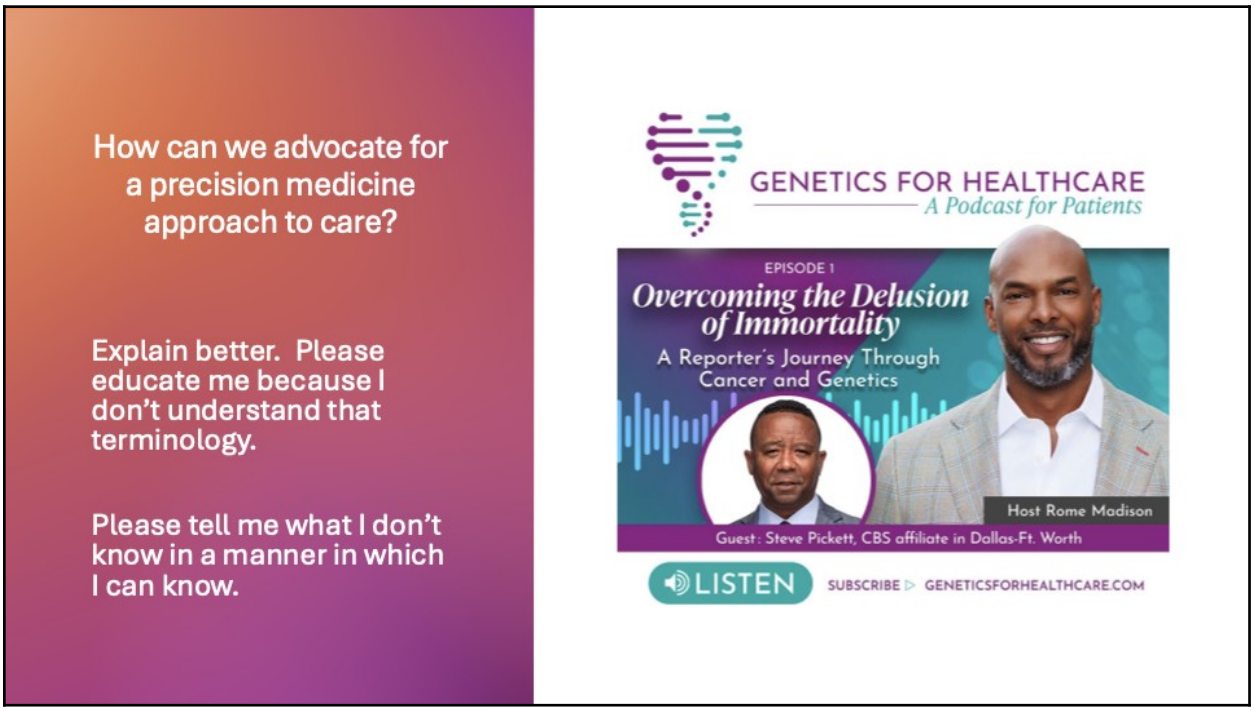
At the time, working for this company, I had the privilege of selling the first assay that informed doctors on how to treat cancer patients, on what's likely to benefit them or not benefit them. It was a fresh tissue assay, which meant that when a patient is getting their tumor resected (surgically removed), we had to take a piece of that tissue in order to get this molecular genetic information that we can get today through an archive block (a preserved tissue biopsy) or blood. But we needed that then. The reason I mentioned that is that was the first company that was ever doing any type of personalized assay to help personalize cancer care. I have over 20,000 hours in the operating room watching tumors being removed from the brain, breast, lung, colon, every organ in the body, on patients as old as 90 years old, and as young as nine months old. Of all of those hours watching surgery, working with doctors, in those early days, it took a monumental effort to get one person to say, “Yes, I'm going to adopt this.” And even when they adopted it, I had to be there to train the folks in the operating room and the pathology department. And then when that report went to the treating oncologist, I had to sit with that oncologist to help them understand how to use these genetic insights and apply them to the care for their patient. That’s the reason I have tremendous respect for healthcare providers who will go the extra mile, who will ask the extra question, who will do those things that may not be convenient, may not be easy, but they will take the time to ensure that patient understands that

I mentioned that my mother raised me as a single parent. I didn't have a relationship with my father until I was 17. But two years into working in this field, my father was diagnosed with colorectal cancer. I advocated for patients every day. I was there, working for somebody's mother, brother, father, cousin. All these patients meant something to me. I saw them as someone who needed to be guarded, to be their warrior, to advocate for their access to this information. Now it was my father. Fortunately, the surgeon who was going to perform the surgery on my father was my customer. I didn't have any expectations. I knew that I was going to advocate for him to get this type of testing. The surgeon called and said, “Do you want to be there for the surgery?” I jumped at the opportunity. I work with this guy. I do this all the time, so it's a little different. To me, it was just like any other day. I had all of my family out in the waiting room with bated breath hanging, and in that moment, it was just so surreal. I was just so grateful to be in that position for my father to advocate for him, seeing the tissue. When he took the tumor out, he showed me, “This is the tumor.” I followed that tumor to the pathology department and watched them give the white glove service. I understand everybody's not able to be in that position. For me, it was surreal when the report and his biomarkers came back, because I understood that he had stood a good chance of responding to the therapy that they were going to give him, and he was not going to be resistant to any of those. The biomarkers were favorable. My father today is a 21-year colon cancer survivor. He had a good molecular report.

I wanted to give you that background to help you understand how unreasonably confident I am that each one of you can use genetic insights to get the care you need, to advocate for yourself, and also share these insights and experiences that will empower someone else to advocate for themselves in that way, because it can save their life and certainly save the lives of future

generations in your family. I believe that we don't accomplish things sometimes because we just don't think big enough. I am a realist. I know that our life is a vapor. My favorite book says we're not here long. It's not necessarily our breadth of years. It's our depth of years. How much impact can we make, not only on our family and the people around us? Your faith and your fighting and your advocacy can make a larger impact on the world around you. So I encourage you guys to to ask those questions and do those things.

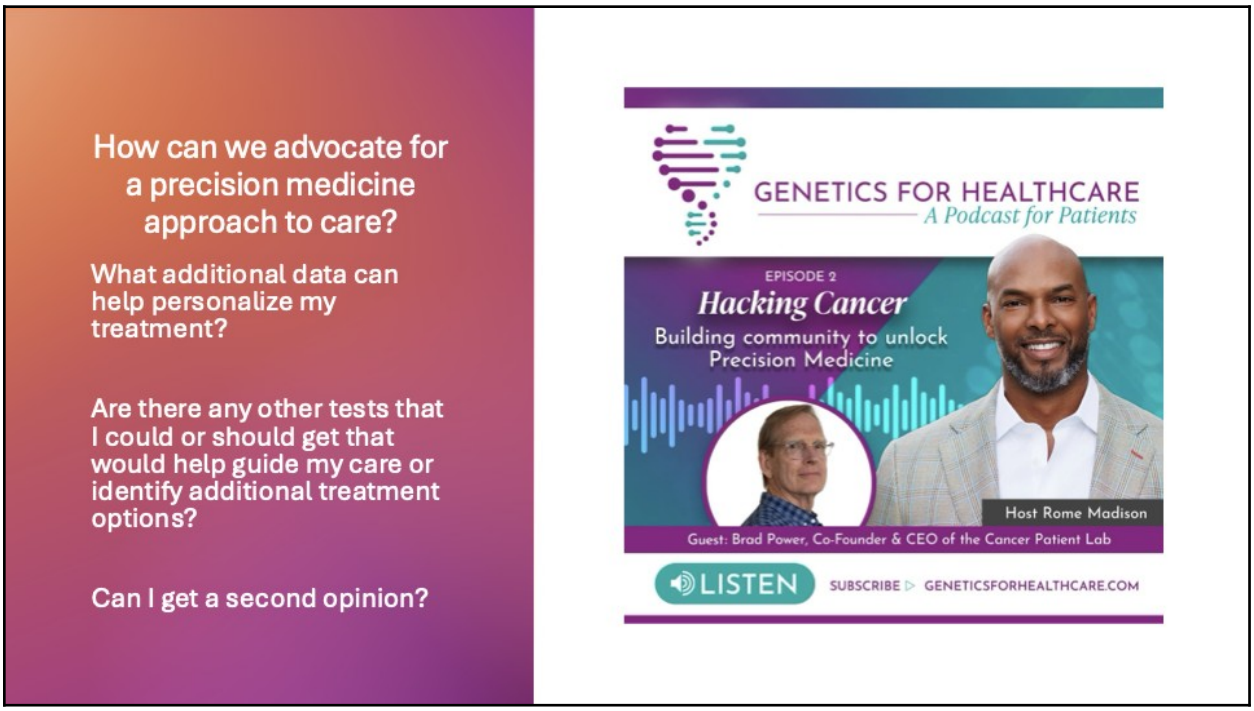
I've had the great privilege to interview a number of people for “Genetics for Healthcare”, my current podcast. When I interview patients and experts for Genetics for Healthcare, at the end of our conversation, I'm always going to ask them, “What are questions that patients can ask their doctor, their care providers, to advocate for themselves?” Many of the questions, at least in these first four episodes that I'm going to show you, are from different perspectives. I would imagine, at some level, the same questions come up, and I would really assume that, because you're here, you guys are a lot more forward with your conversations with your doctor. So these may be questions that you've asked, but I will ask you, if there are questions that you don't see, please let me know what they are, because we want to share them with the world.



This is Steve Pickett. He's in the Dallas Fort Worth area. He is a CBS reporter and anchor, and his story is unique because, being a journalist, he makes his living with his voice. He was diagnosed with prostate cancer, and a year on the end of that treatment, he was diagnosed with throat cancer. He was still being treated for his prostate cancer when he developed throat cancer, and he shared his story on my podcast. I asked him, “What are questions that you can ask?” He has a ton of questions because he's a reporter. That's what he does. He asked questions for a living. He said, “If they're telling you something you don't understand, stop them and ask them to explain it better.” He said, “Educate me, because I don't understand that

terminology.” It is common for doctors to see patients over and over again. They speak “doctors speak”. This is just second nature for them. A lot of times, patients might be in a position where we don't stop them because we're just listening as intently as we can, or the information is just washing over us. That's important, because I believe that people only understand something to the degree that they can explain it to someone else, and if you're using a lot of big terms in medical jargon, that just is not helpful. I didn't go to medical school, so if you really understand this, you will help me understand it.

Another question that Steve suggested is, “Please explain to me, tell me what I don't know in a matter that I can know it.” I think that's a pretty detailed question that says, “Say what you just said in English. I am not a doctor. I'm not your peer, so help me understand. I'm not going to leave here until I confirm with you that I've understood what you said and the implications of that.”



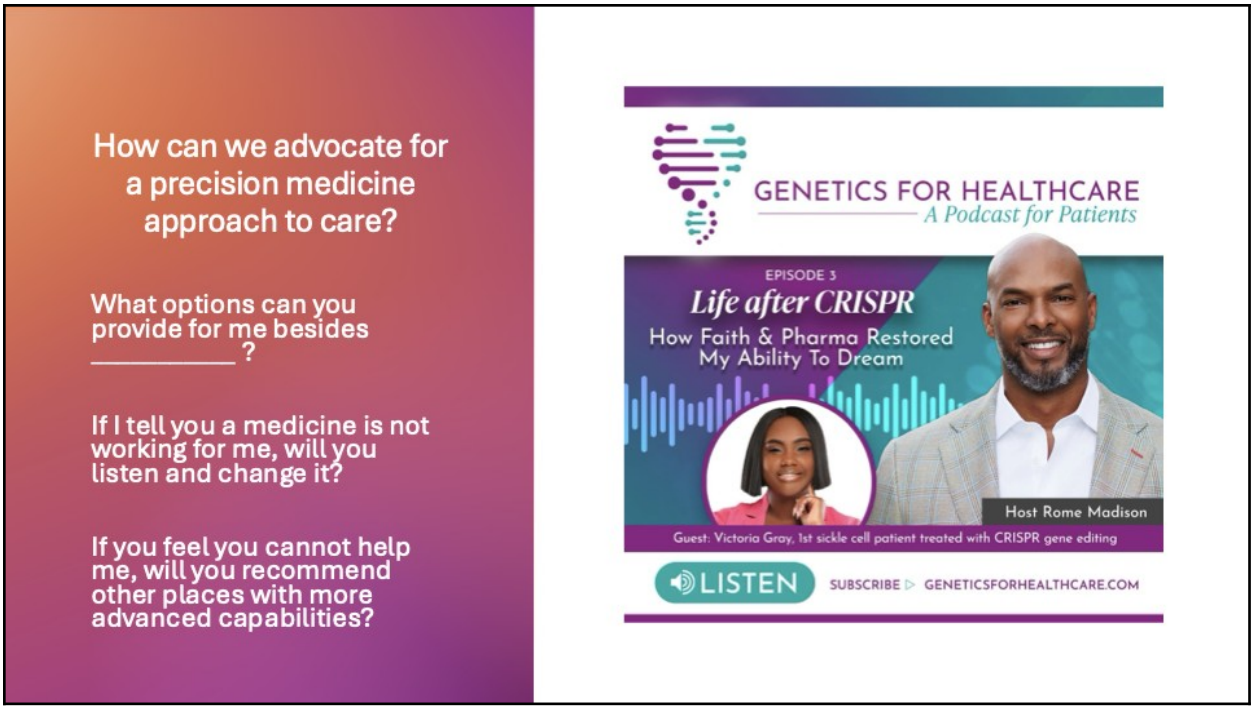
Some of you might recognize this handsome gentleman I had the pleasure of interviewing, as I mentioned, Brad, for this podcast, which will air this week. It's on YouTube now, but we'll do our social media push in the next 24 hours.

What Brad has mentioned is, “What additional data can help personalize my care?” Information, in and of itself, is not powerful. Applied Information is powerful. It's one thing for a doctor to say he has information, but he needs to explain. Then he or she needs to explain what the potential of that information is – how it can be applied.

Another thing that Brad mentioned in our conversation is asking the doctor, “Are there any other tests that I could or should get that would help guide my care or identify additional treatment

options?” What we're talking about here is diagnostics. The fact of the matter is, there are many diagnostics available for patients. In many cases, they're covered. There's a clear indication, but the patient is not told about it, or it's just not ordered, or in some cases – and there's data on this – these tests are ordered, and it may reveal that a patient is a candidate for therapy, but the patient never gets the drug. I understand there are many different reasons why that might be the case.

Another question you should ask, “Can I get a second opinion?” That's key because you want to know that your doctor is for you in your health, in your choices, and that he's willing to be a good partner with you for your health. There are stories that I've heard of doctors becoming offended, like, “You're questioning me?” “Wait a minute. I'm the patient. You're working for me.” We want to make sure patients understand that their voice matters and don't hesitate to use that voice with your care providers to get more clarity and to ensure that they're working with you and they're going to be a partner.

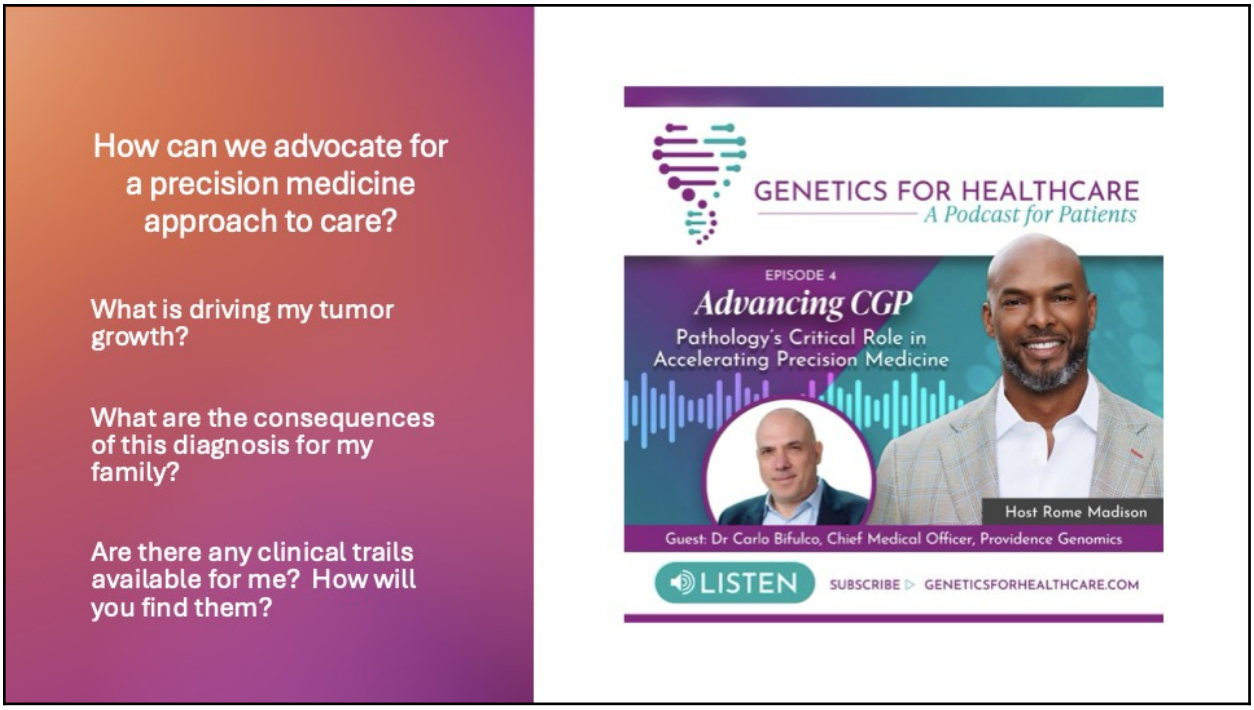


Victoria Gray is the first sickle cell patient that was treated with CAR-T therapy. It cured her of all of her symptoms. She was treated as the first patient in a clinical trial in 2019, and she has not had symptoms or the pain associated with sickle cell since then. It’s a fantastic story that will come out next week. She's not a cancer patient. But her questions are still highly relevant for any patient.

She suggests, “What options can you provide for me besides the standard?” In her case, it was pain medication. Sometimes with lung cancer diagnosis or others, there are targeted therapies, immunotherapies, clinical trials, but what they're offering is traditional chemotherapy, and that's a good question to ask to see what the breadth of treatment options might be.

A second question is, “If I tell you that a medicine is not working for me, will you listen and change it?”

And third, “If you feel you can't help me, will you recommend other places with more advanced capabilities?” She happened to be living in not rural Mississippi, but it was certainly a small town in Mississippi, and they just didn't have the capabilities to give her the care that she needed. In this case, she didn't have the language to ask those questions. It’s very important.



Dr. Carlo Bifulco is the Chief Medical Officer of Providence Genomics. He is a pathologist, a scientist by training. We talked about the role of making sure patients' tumors are getting a comprehensive genomic profile as early as possible.

A great question that he suggested is asking your doctor, “What's driving my tumor growth?” That reflects on diagnostics. It reflects on a genomic profile for your tumor. It's important to ask that upfront, because if they don't know, there's ways that they can know, and you just want to make sure that they're on board for finding out.

“What are the consequences of this diagnosis for my family?” That's a major implication, because many times – as I don't know what your experience has bee – I always ask patients that I interview, “Were you offered germline genetic testing at any time to define if you have a genetic predisposition for developing tumors or cancer?” It's like 60/40, “no” to “yes”. They're just not being informed of this.

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“Are there any clinical trials available for me?” And, “If there are, how will you find them?” Because it is the case that geographically, your institution might not have clinical trials, but there are other institutions that have clinical trials, and they might not be able to find them. They may not suggest them, because it's not in their network, whatever the case may be.

These are ways to ensure to communicate to your doctor that you want them to be a partner for what's best for you.

Here are some additional questions. This is all centered around diagnostics because genetic information is a way to unlock innovative care, clinical trials, and insights that can help future generations of your family avoid cancer diagnosis, or at least detect it early. It's not just limited to oncology. It is spreading to other diseases like cystic fibrosis, neonatal care, neurologic disorders and others. These questions are relevant to all of those situations.

- “If I don't need biomarker testing, why not?”
- “How will biomarker testing be done?”
- “Is liquid biopsy an option for me?”
- “Which biomarkers should be tested?”
- “What can they tell us about my cancer?”
- “Can I get a copy of my biomarker test report?” That's a big one you want a copy.
- “Will I need to have biomarker testing done? And if so, when redone?”
- “How much will the biomarker testing cost, and is it covered by my insurance?”
- “If it's not covered, what options are available to get this information and not cause financial toxicity or excessive debt?”

Again, it's my goal here to really arm you with questions. I would certainly imagine that being here in this environment, amongst these leaders, you guys are probably asking these questions and others that that I may not be aware of, but I really I want you guys to know that you have a lot of people fighting for you, whether you may not know them.

We want as many patients as possible to have access to these innovative therapies and this genetic information, and to ensure that you are working with healthcare providers that have your best interests at heart and are willing to be your partner to do the things that you want for your care.

I'll stop there, and I will leave you with the idea that, again, I have an unreasonable amount of confidence that this can become mainstream, that we will get greater access to this, and through your experiences, someone's life is going to be better.

Cindy Ness 26:50
Thanks for this really inspiring conversation. I too have crazy, unreasonable confidence that we can diagnose cancer better, and act sooner, and eventually get to a pretty overarching cure – not easy, not quick, but I really do as well.

Where I disagree with you, and this is to spur an interesting conversation, not to be in any way critical, is that the answer is going into one's doctor's office with all of these questions. I'll tell you why. I recently had to do a biopsy – and this is at MSK, so in New York City. Their institutions are not set up as they are now, to spend time with patients in the way that would be necessary to get these questions answered the way one would need. Most patients don't know how to ask these questions because you have to have a lot of background knowledge also to understand when you're getting the right answer. I think they're the right questions, and I think there are answers to those questions, but I don't think that most of the doctors – and I'm not trying to be negative – we can get into that's a side conversation as to why, just to say that there are people out there.

The question for me is, “How do you get to the people out there that answer these questions in the way that would really move a patient?”

I'm talking now sort of institutionally, but it's almost like I think we should stop looking for: We go in, we advocate for ourselves. We need different kinds of doctors that are going to value these questions. In fact, if they did, they would be coming to us. We wouldn't have to ask them these questions.

I know that I don't have the answer, and you don't have the answer, but maybe what I want to say is, “Do you see ‘Standard of Care Medicine’ changing, or other places in medicine changing enough where one can go in and have this conversation?”

Do you agree with my premise? Do you disagree? Do you think that overall, we're moving in the right direction? That's my long-winded way of asking simple questions.

Rome Madison 29:39
Yes, you're correct. The current system is not set up because doctors only have so much time and again, patients may not have the background knowledge to know whether an answer that they get is accurate or not. What we're doing here is the idea of spurring the dialog, because right now, these conversations broadly don't seem to be had, because the numbers show that patients are not getting access to this testing, even when there are clear indications through guidelines, and in many cases, coverage through insurance.

Getting the information out there to start a dialog with the doctor is important. Also, if that doctor doesn't have the time or doesn't have the answers, at least that doctor will make a point to follow up or refer you to someone who can answer your questions, because in my opinion, that's how they partner with you. They may not have the answers or be the solution, but if they know you're searching, at least they can be a partner in helping you get the answers that you need, and hopefully discuss them together, whether it's an advanced practitioner or a genetic counselor or any other type of patient. The goal is to start that dialog and to help them understand that it's important to you that you're partnering, and giving you the care and attention that you need in that care.

I would not say that this is the end all and be all. But the goal that we're trying to do is start that critical mass of questions, because the healthcare system will only get there with demand. If patients are asking these questions – in my language “making their doctor uncomfortable” – that's when things happen.

Roger Royse 32:06
You mentioned the example of the patient who was in a small hospital, who might not be getting the best care. The more I get involved in this community, the more I think that is just so true. You can go from one hospital to another and the standard of care can differ, right down the block. I'm wondering, from my perspective, I don't know if you agree or disagree, should a patient be in a very large, university-affiliated medical institution if they have cancer, or maybe they're less likely to be flexible on some of the things you're suggesting? Or does it really matter? What's your experience with that?

Rome Madison 33:00
My experience is in the continental United States, managing teams, talking to doctors, going everywhere to talk to physicians about adopting these innovative tests and therapies. I live in Texas, for instance, and a big customer that I've worked with in the past has been Texas Oncology. Just to take one instance: referring to genetic counseling for germline genetic testing. Of their 600, or 400 locations, or whatever, I don't know how many they have now, but as of three years ago, I think they had six genetic counselors, and the wait to talk to a genetic counselor is six months or more.

It's not standard that the care would be inferior because those doctors have the same access to the therapies and information that large academics centers have at a base level of treating

cancer patients. But when you're talking about advanced cancer clinical trials, understanding what's innovative, at the academic centers you're dealing with a specialist. Your community oncologist, who sees and treats every cancer, every tumor that comes in the door, may not have the same experience and knowledge of treating head and neck cancer as a head and neck specialist at MD Anderson or UT Southwestern here in Dallas, because they see that all day, every day. They treat that. That's all that they deal with. They know the studies. They know the data. They know what's coming. In that way, it can be an advantage.

However, when you're going into the community setting, it's good to ask those questions, because they may not be as forthcoming, because, again, they have 30 patients they have to see. “I've got 15 minutes with you. I just want to make contact and get you started. I want to let you know that we're going to care for you.”

But again, introduce those questions, because it might start a larger conversation or get additional resources that they have available to you sooner, or refer you to someone who has a little bit more knowledge that can inform your care. We don't know what we don't know. Going into that situation, we're just there for the doctor to speak to us, to learn what the doctor has and what their perspective is and what their plan is. This is why we do this, to build community, to encourage others to be empowered through information, to ask these questions.

Roger Royse 35:59
Going to the chat, I won't read the entire comment, but there's a part of it that is particularly relevant here. It says, “Should they have done more molecular genetic testing on new tumors, or can you assume they carry the same information?” The reason that's relevant: I know that when I was in treatment, I got a genetic testing report, and it said, “Here are the mutations.” Nobody told me there was anything more than that. I learned through the Cancer Patient Lab, about Tempus, BostonGene, and the proteomics report, and every one of them had a little bit more information that was super helpful.

There's always a question here: “How much testing is enough?” People might get a false sense of security once they get the genetic testing and they get one report and call it a day. That's my comment. I don't know if you have any response to that or not.

Rome Madison 37:03
It's a very good comment because in my conversation with Carlo Bifulco, he talks about the variability and the unwanted variability. There's variability in testing. Upon diagnosis, they may run two or three biomarkers and wait for a comprehensive biomarker test that might be 500 to 1000 biomarkers at later stages of disease. If you're talking about a lung cancer patient, where you can't get a lot of tissue potentially, why don't you run the 500 gene biomarker test so you can get as much information up front as possible that might inform care?

Something to think about here is many times – and we're talking about germline genetic testing. Those are the genes or gene mutations that you're born with, you've inherited, versus those mutations that evolve through any unknown reasons. They continue to evolve through drug

pressure, through \ the evolution of how cancer cells continue to mutate, and they want to become immortal. Those mutations can increase between first line therapy and recurrence. Upon recurrence, it may be wise to get another profile on the tumor tissue that exists. But then that presents challenges in itself, because they may not have access to the tumor based on where those lesions are, or it may be harmful or dangerous to try to get tissue in order to get that information. But there's still liquid biopsy available that may be an option.

So again, at every turn, we just want to go in and ask these doctors the questions so they can share with us what we feel is available. Indeed, it's advocacy. It's self advocacy. We have to do the work, the research for ourselves. Get folks involved. This is a great forum to come back with some of those answers to the questions to vet that.

Roger Royse 39:29
Rick had a comment, and it's kind of similar to Chris's. Rick's comment is that we cannot control the doctors, so we have to advocate for ourselves at the same time and can work with diagnostic companies to do a better job educating doctors.

Rome, you started out in diagnostics. What does that feel like now?

It just seems to me that the technology has maybe gotten too good. It's picking up noise at this point. Can you talk a little bit about that?

Rome Madison 40:06
It's the realization of that unreasonable confidence that I had years ago that we can make progress. I never saw AI coming. I never saw a next generation sequencing coming. When I started in the business again, that was like version one of the tests, where you needed fresh tumor cells to be able to get this type of genomic information to inform care. Now we can get this information any number of ways.

The way that AI is coming into the space, I have to admit, I was a little leery, kind of suspicious, like, “Okay. Come on now.” But in terms of workflow, in terms of the timely intervention that is needed at a point in time and care, in terms of that physician who lives in, Duran, Oklahoma, who may not have the knowledge about pancreatic cancer as the pancreatic cancer specialist at an academic institution, that can help bridge the gap for those doctors who are in those situations. It gets us faster to a tipping point to where this information is readily accessible, and we can integrate these genetic and genomic insights into our healthcare, and not just one time. It can be in our record. We can own those records ourselves as patients and take them in a way that's not just a .pdf report that the doctor doesn't have time again to thumb through. It can be very dynamic in the way that technology is advancing diagnostics today.

Roger Royse 41:51
I want to relate one experience I had for you, to give you an example, to kind of double down on what you just said. I got a proteomics report that I learned about again through Cancer Patient Lab, long after my chemo and my surgery and had some tumor tissues still sitting around, and I

got this big, thick report, and I didn't really understand it at all, even the summary. I gave it to my oncologist, who was a really good doctor. I have really good doctors, and he emailed me back, and he said, “What am I supposed to do with this? I don't even understand it.” That's what he said. I took it to one of the cancer scientists that works pretty closely at Cancer Patient Lab, and she said, “Go back to oncologist and tell them to look at page three, line 26. Tell them to look at this specific thing. Just tell them it's TROP2. And this is the treatment.” I went in, and I sat down with him in person, and I highlighted it. I said, “I've been told to tell you to look at this.” He looked at it for a minute, and said, “Oh. You have that. Okay. Well, we know what to do if this recurs.” That really struck me that that I had to do that much work to find out that I'm a candidate for targeted therapies, or I might have been.

Is my experience unique, or is that how is how it is out there?

Rome Madison 43:35
It's not unique. That's the importance of having these conversations. Because somewhere, if we're seeking, we will find the information that we need and that we're looking for. It's so important that a doctor says, “I don't know.” I was talking to Steve Pickett, and he said he mentioned that his wife doesn't like his urologist, because he says, “I don't know.” “Your doctor is supposed to have the answers.” But to Steve, he was like, “That's important to me to know that someone is willing to be transparent about what they don't know so we can together find out.” So it's unfortunately not uncommon that they may not know or be familiar with these insights or these new diagnostics, and it's also, unfortunately, not common that many in your position don't continue to ask and seek that information. Kudos to you, and kudos to your doctor for working together.

Rick Davis 44:50
We run across patients in several different diseases, who frequently have to inform their doctors. Sadly, usually this is not at centers of excellence. I suspect that Roger was at a center of excellence and it happened. It can happen at centers of excellence, but it's less frequent, but at the same time, an educated patient is going to get much better treatment than an uneducated patient, because they're going to know what test to ask for, and they may possibly know about certain precision targets that the doctor hasn't come across before. Because doctors, after all, are human.

There's a couple of issues that this raises. Number one, if you can try to get to a center of excellence by and large, you're going to get better treatment.

Number two, try and stay on top of at least the basic tests. One of the things that Hazel's raised a couple of times is, “How often do I need testing? When should I get tested?” A lot of that depends on your disease. In prostate cancer, for example, somatic mutations change all the time. Many years ago, when Medicare first approved somatic testing, it was once in a lifetime, and we went back and we campaigned with Foundation Medicine and others, and they changed it to as needed and recommended by the doctor. So now, in some cases, you may need to get somatic testing every six to nine months, because the cancer is morphing constantly. It's

changing. It's dynamic, and so mutations that you had three years ago may not be the mutations you have today. With precision medicine, you need to know what you have today.

I don't know enough about ovarian to know how quickly it changes there, but that's the conversation to have with your docs. How frequently do the mutations change? It sounds to me, Hazel, that what they're saying is, “Well, if you have recurrence, that probably means that the mutations might have changed.”

One thing, just for your information, is that they pretty much have found that liquid biopsies and tissue biopsies are consistent. So whatever you find in your liquid biopsy is most likely going to be found in your tissue biopsy, certainly, if it is a soft tissue. There's a problem with tissue biopsies from bone, because they've got to macerate the bone, and that can mess up how the mutations show up. But ideally, especially as the technology improves, what they're collecting from blood is going to give you the best view.

The other thing I wanted to say, Rome, is I put a note to you in the chat window. Hopefully you'll look at it. We do a lot of work with “remomidlary carcinoma” (?), and we'd love for you to give that a plug when you interview Vicki Victoria Gray, because it' just doesn't get enough publicity, and it's just a nasty disease, which is correlated with sickle cell.

Rome Madison 48:47
Thank you for that information.

Roger Royse 48:51
Rick was focusing on Hazel's comment that her oncologist and surgeon said they discourage her from getting a liquid biopsy. They said the information could be incomplete and confusing and won't lead to anything useful. Hazel says she was talking about CTC testing.

Are you able to comment on some of the specific types of liquid biopsies that are out there and how they compare, because maybe that's what they were reacting to as a circulating tumor cell test.

Rome Madison 49:27
There's limited data on CTCs in specific diseases, and that's many times what clinicians are going to look towards is like, “In the disease that I'm treating, how do I apply that information?” But I will say that for a doctor to say, “Well, it's not going to help.” How would you possibly know it's not going to help? How would you possibly know? If I'm your patient, and I'm asking you about it, I would want you to say, “Listen. I don't have a lot of experience with it. I've not heard any data that's compelling for me. But if you feel that it's useful, let's look into it or something.” But I don't want a doctor to summarily dismiss it because he may not be familiar with it or hasn't had great success with it.

Roger Royse 50:24
More than that, I want to know, “Why?”

Rome Madison 50:29
I was talking to a breast cancer patient who asked her physician, “Will you be doing genetic testing for me?” And the physician said, “Oh. You don't need that.” “All right. Well, why not?” “Well, it's not going to change what I do. Okay?” The answer was, “It's not going to change what I do.” It's not that it's not beneficial for you, or could be informative for you. It's that I'm not going to do anything with it. Again, we're talking about advocacy, and to arm yourself to say, “Hey, are you my partner? Are you treating me? If I feel the information is useful, even though you may not use it, someone may use it. So this is why I want it.” I'm very curt with physicians who summarily dismiss things when they are supposed to be working on my behalf. That's just me.

Robb Owen 51:35
I was curious as to how much advocacy you see looking at it from more of the natural side, as far as nutrition and supplements. Most doctors don't seem to have the expertise or the knowledge behind how effective those methods can be.

What are your thoughts on how to approach a doctor with information and relevance on that and get some productive feedback?

Rome Madison 52:09
I'm not quite sure that many MDs, who are trained in Western medicine, will take that into consideration. There's just not many. It's not a part of their guidelines. It's not a part of their training. So they may not be as receptive. Certainly some will be. But I will also tell you that I'm married to a naturopath, and she is all about it. There are naturopathic clinicians who will give you a consultation on the different holistic or nutritional things that you can do to help fortify your immune system, build your strength, and fight disease. I'm in favor of all of it because when is more information a bad thing?

Robb Owen 53:08
That's what we do with what I work with. I use artificial intelligence to develop targeted n-of-one protocols related to the specific mutation. Hopefully we can have further conversations about this, but using that as a template to share with doctors, I'm hoping, with the information we provide the client, sharing iy with the doctor, we can bridge a gap in that respect. But your wife would find this very interesting. I believe we have a naturopathic doctor on our team and nutritionists as well. The relevance of that type of information is seeming to have pretty significant success when combined with conventional Western medicine.

Rome Madison 54:01
I want to circle back around quickly to Hazel's comment on the question that Roger asked around other types of diagnostic testings, like CTCs versus circulating tumor DNA. The data is progressing quickly with circulating tumor DNA, otherwise known as MRD testing, molecular residual disease. Some call it “minimal residual disease”. It has many different applications, and the evidence behind that is that it seems to be more robust than circulating tumor cells. But even though I say that the adoption for MRD testing is extremely poor, doctors aren't familiar

with it. They don't know what to do with it. Many times they might hesitate to order it because they would rather do something else first. And so again, more advocacy is needed to ensure that these doctors are willing to be our partners in our care.

Chris Apfel 55:12
I wanted to comment on liquid biopsies and additional testing, and I also put a little bit in the chat for Hazel. In general, genomic testing often doesn't yield actionable information. If you look at the NCI MATCH trial, published by Keith Flaherty from Harvard, only one in four patients has an actionable mutation. Number one. That's a real, real problem, which is one of the reasons why SageMedic is doing functional precision medicine, the next generation of Oncotech, which you might want to hear about.

The the other part is: if you have a rare disease, why not? Why leave a stone unturned? If you have a rare disease, especially then I want to have the Genomic Test. Number one. Number two, I'm not very familiar with how well now the liquid biopsies are correlating with the solid tumors. There were initial reports that didn't show very good correlation, and there were certain concerns about the validity that probably has now been overcome in the last 10 years. I would like to say, I would like to hope and so in general. Now probably the liquid biopsy would be the next part to look at circulating tumor DNA and I would definitely do that. It's relatively easy to do. It's more or less non-invasive. When it comes to circulating tumor cells, they are usually circulating in a 10 ml vial. You get probably a median of about 40 cells with a really good isolation technique for tumors that are late stage, phase IV, that are heavily shedding, such as prostate or breast cancer. But for most others it's relatively rare, and so you actually only have a few cells that you can isolate with circulating tumor cells. So that's probably not the most viable approach. It makes sense to do a liquid biopsy to look for actionable mutations and see whether there are any. There's nothing to lose from it. So I fully agree with what you're saying, Rome.

The second part is MRD, minimal residual disease. There is Signatera and Personalis. I saw that Hazel is in France, and I thought, “Okay. It doesn't matter.” But the challenge is that Singatera is not on the standard panel yet, and they're doing a phase III or whatever study with colorectal cancer patients in France that is currently underway, and they're doing some assessment, but I would think that if you live in France, probably the only way to get Signatera would actually be to contact the company, and it will likely mean paying out-of-pocket. I've also heard that Personalis has an even superior technology to monitor your progression of the disease or whether your tumor is really responding to the treatment. Because it's really important not to treat with drugs that will only hurt you and can't help you.

Cindy Ness 59:12
These are the right questions to be asking for patients really advocating and learning how to advocate for themselves, and that's a very long process. Sometimes in terms of advocacy, patients help each other and find out on a chat board, “I have pancreatic cancer, and this is the best person to see because they answer all of these questions.” Patients often lose time asking questions, not getting the right answer, taking a while before they realize they didn't get the right answer. Now maybe a month or two has passed. It's putting a lot on the patient to figure out

what the right answer is. They got the right answer. I worry for patients. I work with patients. I worry for them.

This is a question for Brad: do we have, or why don't we have, or could we have, or should we have, a repository of doctors in various areas: pancreatic, prostate, breast cancer, etc., that are the kind of doctors that are already there?

You don't have to create them. We have enough experience amongst ourselves, and it's probably collectible from others who are not part of this group of beginning to put together that kind of a resource.

Roger Royse 1:01:00
We're working on that, in fact, behind the scenes. It's a challenge. Brian McCloskey, when he was alive, had done a really good job of putting into spreadsheets all of the partners that we work with. That's how I found a proteomics test, for example. We're in the process of making the Cancer Patient Lab a much more robust resource right now, and including those sorts of directories with comments and feedback and things like that. It's a long process, and it's all volunteer-driven, so it takes a little longer, but stay tuned.

Cindy Ness 1:01:41
That's great.

Roger Royse 1:01:44
I want to thank you, Rome for being here. Thanks everybody for your comments and your questions. Rome, I put the link to your website [https://romemadison.com/about-rome/] in the chat, so people can find you and can subscribe to your podcast and follow you and reach out to you if they'd like to talk further. I think a couple people do want to do that. This has been recorded, so this will be on the YouTube channel, and we're going to put these links in the notes as well.

“Self-Advocacy in the Era of Precision Medicine” (Rome Madison) [#133]

CHAT DISCUSSION

00:43:08 Cancer Patient Lab: here is Rome's info - https://romemadison.com/about-rome/
00:43:39 David Plunkett: Reacted to "here is Rome's info ..." with 👍
01:05:29 Dr. Chris Apfel: Wonderful to hear you started out at Oncotech, so you might know Dr. John Fruehauf (our acting Chief Med Officer) and Ricardo Parker (our Dir of Cancer Research). Let's connect soon and have a 1:1. Best way to reach me is capfel@sagemedic.com.
01:08:44 Rick Davis, AnCan Foundation: We cannot control the doctors... so we have to advocate for ourselves. At the same time, AnCan is working with some of these diagnostic companies to do a better job educating doctors.
01:11:59 hazel: Thank you, Rome. Question regarding tumor testing:
I had two surgeries prior to my chemo. First one took out the ovaries and fallopian tubes to diagnose a very rare ovarian cancer for which there is little information or cure.
The second debunking surgery two months later, found four small tumors on the peritoneum.
For the molecular profile, on one of those tumors - they did the BRCA 1 and 2 tests. That’s it.
Should they have done more molecular/genetic testing on those new tumors or is it correct to assume that those tumors carried the same information and cancer as the first surgery?

By the way, the first surgery’s pathology reading showed
DX: Mesonephric-like adenocarcinoma ovarian origin suspected:

p53 wild type,
PAX 8 POSITIVE;
GATA3 AND TTF1: HETEROGENEOUS
CK7 MULTIFOCAL
P16 PATCHY EXPRESSION
MMR - PMMR
RO AND RP BOTH 0.

Next Generation Sequencing:
BRAF p.Gly469Ala mutation (VAF=37 %)
KRAS p.Gly12Ala mutation (VAF=37%)
01:15:58 Dr. Chris Apfel: Cindy, I wholeheartedly agree with you. My thinking is that very understandably patients don't have enough background knowledge on their disease to even ask the right questions, physician's don't have the time (and are not incentivized) to educate them and if they are answering the question, most often it is not properly understood by the patient because of limited background knowledge. In short, it's a vicious cycle. The system at the MSKs of the world is not setup to have the time so at the end of the day, patient education AND advocacy is really critical. That's why patient's need support groups and advocates because it's generally way too much for an individual to handle.
01:19:48 hazel: Question re liquid biopsy: I’ve had chemo and am now on AVASTIN, when I ask for liquid biopsy, oncologist and surgeon says on my cancer type (rare ovarian

cancer mesonephric-like adenocarcinoma) the information could be incomplete and confusing and won’t really lead to anything useful. But it may be useful to do it if/when there is a recurrence.
01:26:59 hazel: I think I meant to say circulating tumor testing - if that’s not the same thing as liquid biopsy
01:27:03 Dr. Chris Apfel: Hazel, generally speaking only 1 out of 4 patients have actionable mutations that might suggest a targeted therapy.
However, especially if you have a rare cancer, why leaving this stone unturned?
Second, there are liquid biopsy approaches that can be used to monitor your tumor response (Personalis, Signatera). It's now also covered by most insurance companies.
01:28:05 hazel: Replying to "Hazel, generally spe..."

I live in France
01:28:19 Dr. Chris Apfel: Ca ne fait rien.
01:28:35 ari akerstein: Replying to "Hazel, generally spe..."

Can you say more? What are the constraints on getting reimbursed by insurance (e.g.., Is it the friction of asking the doctor for it?)
01:29:05 hazel: Replying to "Hazel, generally spe..."

I’m not sure Signatera exists here. I’ve seen a FB group about this test.
01:29:48 ari akerstein: Reacted to "I’m not sure signatu..." with 👍
01:31:54 Ryan Ramanujam: Have to run, thanks for a great presentation and discussion Rome!
01:32:17 Dr. Chris Apfel: Replying to "Hazel, generally spe..."

Natera announced a collaboration on the CIRCULATE-PRODIGE-70 study, a Phase III clinical trial in France assessing MRD-guided adjuvant treatment in stage II colorectal cancer patients. So, that might be a heavier lift, including an out of pocket pay.
01:33:16 hazel: Replying to "Hazel, generally spe..."

@ari akerstein I had scans last week, they were negative. I’m still on avastin which tackles the VEGF as . But I asked my oncologist what is taking care of my KRAF and BRAF mutations, she said for my cancer they don’t have anything, they have it for other cancers. So I asked for circulating tumor testing and she said again, we won’t find useful information because we don’t know enough about your cancer. If you have recurrence than we can think about it. I know this sounds confusing. I was confused.
01:35:03 hazel: Replying to "Hazel, generally spe..."

Even more confusing is that I have heard previously from the other drs on the team that circulating tumor testing are done more in research in France, but my oncologist last week contradicted that to say it is available- just not useful for me.
01:35:20 Cancer Patient Lab: Replying to "Hazel, generally spe..."

“Self-Advocacy in the Era of Precision Medicine” (Rome Madison) [#133]

I view recurrence as including something showing up on a liquid biopsy
01:35:35 ari akerstein: Reacted to "I view recurrence as..." with 👍
01:35:44 ari akerstein: Reacted to "Even more confusing ..." with 👍
01:37:06 ari akerstein: Replying to "Hazel, generally spe..."

@hazel it’s confusing indeed
01:38:08 ari akerstein: 100% @Cindy Ness re: the time element
01:40:01 Brian Kane: Thank you Rome!